



STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

TESTIMONY PRESENTED BEFORE THE COMMITTEE ON PUBLIC HEALTH

March 11, 2011

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House Bill 6548- An Act Concerning the Collection of Data by the Office of Health Care Access Division of the Department of Public Health

The Department of Public Health supports House Bill 6548, provides the following information, and requests an amendment to this bill to clarify the intent of the department to ensure the confidentiality of patient-identifiable data in the possession of the Office of Health Care Access division of the Department of Public Health. The Department would like to thank the Public Health Committee for raising this bill.

The Department of Public Health (DPH) supports House Bill 6548 which would prohibit the disclosure of patient identifiable health information except for medical and scientific research as permitted by section 19a-25 of the CGS; and would permit the Office of Health Care Access to create public use files containing only de-identified hospital discharge data that is currently collected by OHCA.

The thirty acute care hospitals in the state are currently required to submit administrative and patient billing data to OHCA pursuant to General Statutes § 19a-654. Section 19a-654 requires OHCA to keep confidential individual patient and physician data, and permits the disclosure of aggregate reports from which individual patient and physician data cannot be identified. As OHCA already collects information, it should be noted that House Bill 6548 is incorrectly named: the purpose should be revised to reflect the *release* of data as discussed below rather than the *collection* of data.

Under General Statutes § 19a-25, DPH may disclose identifiable data for only medical or scientific research, with another governmental agency or a private research organization, provided there is no further release of that personal data by the research entity. Sections 19a-25-1 through 19a-25-4 of the Regulations of Connecticut State Agencies establish a formal process and clearly defined procedures for ensuring the confidentiality of such personal patient information. DPH's Human Investigations Committee (HIC), based on strict criteria, approves or denies identified data requests for medical or scientific research. Consistent with § 19a-25, House Bill 6548 would allow personally identifiable data collected by OHCA per § 19a-654 to be released only for legitimate medical and scientific research, and only after the DPH HIC has thoroughly reviewed and approved the request. The department shall not disclose identifiable data unless an individual, organization, governmental entity in this state or another state completes a written application with required information, discloses that the data is required for medical or scientific research, has entered into a written agreement to protect such data, and returns or destroys all identifiable health data provided by the department. Please see attached for data elements excluded by type of data release.

House Bill 6548 would provide OHCA data with the same stringent confidentiality protections that protect other health information maintained by the Department, and would also align the State of Connecticut's policy on release of "de-identified" hospital discharge data with that of more than 23 other states, including many of Connecticut's neighbors -- MA, VT, NH, ME and NY. It would allow for the creation of a public use file that would permit OHCA to release a limited data set stripped of personal, physician, and

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insurance plan and hospital identifiers to certain approved entities wishing to conduct their own analyses. For example, a policy analyst attempting to measure a particular health care policy's impact on various demographic groups or a health care service provider attempting to identify specific health care services needed in a defined geographic area could utilize a public use file for the benefit of the state's residents. Aggregate reports that OHCA currently provides often do not lend themselves to such in-depth analyses and do not afford the analytical flexibility of a public use data set.

In summary, House Bill 6548 would balance the need for both identified and de-identified data with the public's privacy concerns. Ultimately, the bill would permit the department to better fulfill its mission of improving the health and safety of the people of Connecticut by providing information critical to the prevention of disease, injury and disability.

The Department respectfully recommends the following change to the language to subsection (c) to further ensure the confidentiality of OHCA's health information:

The office shall only release de-identified patient data or aggregate patient data to the public. Such released data shall exclude provider, physician and payer organization names or codes. The Office [may release] is prohibited from releasing patient-identifiable data except in accordance with section 19a-25 and regulations adopted

The Department looks forward to working with the committee, legislators and interested parties to ensure the confidentiality of the data.

Thank you for your consideration of the Department's views on this bill.

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Data Elements Exclusions or Replacements for Types of Data Releases

What is currently excluded from or replaced in non-confidential aggregate reports		Exclusions or replacements in proposed de-identified data	Confidential or limited data releases subject to review and approval of DPH Human Investigations Committee (HIC) Policies and procedures follow federal research guidelines
Medical record number		Medical record number	Subject to C.G.S Sections 19a-25 and DPH Human Investigation Committee (HIC) recommendations -HIC is DPH's Investigation Review Board -Comprised of 12 internal and external members including researchers and non-scientific members -Meet monthly to review research protocols on case-by-case basis -Policies and procedures for review based on federal guidelines -Researchers must justify need for any confidential data -Stringent safeguards to protect data must be in place -Only data necessary to conduct legitimate and meritorious medical and scientific research is approved
Patient control number		Patient control number	
Hospital code		Hospital code/name	
Date of birth (replaced with age ranges of 5 or more years and an age group 90+)		Date of birth (replaced with age ranges of 5 or more years and an age group 90+)	
Date of admission and discharge (replaced with length of stay or average length of stay)		Date of admission and discharge (replaced with length of stay)	
Date of admission or discharge (replaced with fiscal year/quarter)		Date of discharge or admission (replaced with week/month/fiscal year/quarter)	
Zip code (replaced with a town or an aggregation of a least two contiguous zipcodes)		Zip code (replaced with patient town)	
Attending practitioner name/code		Attending practitioner name/code	
Operating practitioner name/code		Operating practitioner name/code	
Payer Identification (replaced with broad categories of source of payment)		Payer Identification (replaced with broad categories of source of payment)	
Birthweight (replaced with birthweight group)		-	
Information or data based on fewer than six individual patients, as defined by patient ID		-	
		Procedure dates	
		Sensitive diagnoses (HIV, sexually transmitted diseases, mental health, substance abuse and intentional injuries)	